The role of specialist nurses for organ donation

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The Role of the Organ Donor Transplant Co-Ordinator and the Emergence of Specialist Nurses- Organ Donation, in the United Kingdom.

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The role of Specialist Nurses for Organ Donation: a solution for maximising organ donation rates?

Abstract

Aims: To explore the role that Donor Transplant Co-ordinators have played, and the future potential of Specialist Nurses for Organ Donation (SN-ODs), within organ donation strategies in the UK and other countries.

Background:

Organ donation and transplantation rates vary extensively around the world. However, there is a universal shortage of deceased donors, prompting different approaches to increase transplantation rates. Within the UK the Clinical Lead for Organ Donation and Specialist Nurse for Organ Donation undertake a key role in the implementation of the Organ Donation Strategy. The Human Transplantation (Wales) Act 2015 is a recent development which facilities a deemed (presumed) consent approach to organ donation, the Specialist Nurse for Organ Donation undertakes a major role identifying the potential donor in this situation by confirming the deemed consent status of the donor and supporting bereaved relatives. UK governments in England and Scotland are currently seeking legislative changes to an opt-out system of organ donation, in line with the Wales change.

Design: This discursive paper explores the role from Donor Transplant Co-ordinator to Specialist Nurse for Organ Donation (SN-OD) within organ donation policy in different settings, but with a specific focus on the UK. The paper clarifies the current and future potential of nurses working with bereaved families when requesting authorisation for donation.

Implications for Nursing: The current scope and future potential of Donor Transplant Co-ordinator and Specialist Nurse for Organ Donation roles needs better recognition. Little empirical data exists about the key role that these nurses play in the organ donation process, especially in relation to gaining authorisation to proceed to donation.

Conclusion: There is a need to clarify the role of the Specialist Nurse for Organ Donation and their impact on improving rates of organ donation**.**

Key Words: Ethics, Transplantation; Specialist Nurses; Nursing Roles;

What does this paper contribute to the wider global community?

- The paper highlights the role of specialist nurses in organ donation by comparing their role in the UK and making comparisons with other countries with different donation rates.
- Identification of topic areas in need of further research about the role that specialist nurse play in facilitating national donation policy.

Introduction

For individuals with end stage organ failure transplantation may offer the best and often only option of medical treatment. However, the increased clinical benefits of transplantation, highlighted by good health-related outcomes, are not available to all patients. Globally, rates of deceased organ donation vary and living donation is not prolific in all countries due to differing cultural and religious beliefs. In a minority of countries living donation only occurs where religious and moral beliefs preclude deceased donation. The pressure to increase the number of available organs is being felt around the world, as there is a scarcity of deceased donors. This has led to the development of strategic initiatives to increase organ donor rates, raising extensive international interest in recent years at both governmental and professional levels. This interest is primarily driven by two key factors; the universal organ shortage and wide geographical variations, and the need to ensure that all transplantation activities are conducted in an ethical manner, with equity and safety issues considered essential.

In some countries there have been practices identified, such as payment for organs and organ trafficking, which have gone beyond what is considered universally acceptable in a legal or moral sense. This has led to the development of political and professional requirements to define transplantation practice and to ensure that it has a robust legal and ethical basis (Rudge et al 2012). Professionally, the international response has been co-ordinated

through the establishment of donation societies, spearheaded by the Transplantation society.

This discursive paper aims to provide a balanced and objective overview on the role of the organ donor transplant coordinator (normally a nurse) in this context. Whilst based on international perspectives, specific attention and critique is given to the emergence and potential of specialist organ donation nurses in United Kingdom. We suggest that global development in this clinical speciality is a useful background to consider recent developments in UK.

In the UK, where organ donation rates were historically low, the Organ Donation Taskforce was established to facilitate an increase in organ donation activity. This Taskforce published a report in 2008 which contained a series of recommendations regarding identification and referral of potential donors, donor co-ordination, organ retrieval, legal and ethical issues, training and strategies which generate public recognition, and promotion of donation in the United Kingdom (UK)(Organ Donation Taskforce, 2008). A five year evaluation of these measures reported an increase of 50% in deceased organ donors and a 30.5% rise in transplants being achieved during that time (NHSBT, 2013). Implementation of these recommendation included the training of Specialist Nurses in Organ Donation (SN-ODs), the establishment of a UK-wide network of Clinical Leads in Organ Donation (CLODs), and the improvement of the National Organ Retrieval Service. In addition, twelve regional collaborative centres comprised of intensive care staff, SN-ODs, donation committees, retrieval surgeons and recipient co-ordinators worked together to overcome local challenges and improve donation practice. Following this success, in 2013 a new guide 'Taking organ transplantation to 2020: a detailed strategy' also proposed progressive strategies to further enhance current standards by reinforcing the SN-ODs role in supporting the families of potential donors, improving organ retrieval and transplantation, enhancing survival rates of recipients, and further developing systems that supported these processes (NHSBT, 2013). According to the Scottish Government (2018) 2.4 million people in Scotland have joined the NHS Organ Donor Register, and the percentage of family's consent to donate grew slightly from 53.9% in 2014/2015 to 57.1% in 2015/2016. By 2016/17 this figure had increased again by 34% As of April 2018 there were 2,486,216 people on the organ donor register in the UK. On July 31st 2018 the number of people waiting on the list is 6050 (NHSBT 2018) Possible explanations for these results may be the implementation of the aforementioned strategies, as well as an increase of living donors, effective social media campaigns, and enhanced current social awareness in Scottish society. Nonetheless, more research will be required in order to that understand and build on the current situation to improve donation rates further in the longer term.

The taskforce also recommended that SN-ODs would undertake key roles in the liaison and education of staff within critical care and emergency care areas to promote the early identification of a potential donor and implementation of the organ donation procedure (DOH 2008). On the identification of a potential donor a review of the Organ Donation Register (ODR) would follow, to establish whether a potential donor

was on the register, or had lodged any objection to donation on the ODR. This would then be followed up by an approach to the family for consent. The SN-OD would support the bereaved family through the organ donation process and beyond the SN-OD would also be available for support to those families who had refused donation.

In 2016 the Welsh Government took this approach further by introducing new organ donation legislation, The Human Transplantation (Wales) Act 2015 adopts a deemed (presumed) consent approach to organ donation. There are many professional, operational and ethical implications of this change including the approach and requirements of the SN-ODs in the facilitation and application of the new legislation. This move has also had an impact on the legislation stance from the other UK countries with both England and Scotland recently presenting Bills to amend legislation in favour of an opt-out system in each country. Despite these developments there is limited research about the changing role of the SN-OD, or the vital part these practitioners play in the enactment of organ donation policies and processes across the UK.

This discursive paper addresses three key areas around the role of SN-ODS and their involvement in improving organ donation rates in the UK. Firstly, a review of the history and development from the original donor co-ordinator (DTC) to the SN-OD role, both from a UK and international perspective. Secondly, to clarify the contribution of the SN-OD in the implementation of the Organ Donation Strategy within the U.K., and in the new approach to organ donation in Wales (and the likely extension to the rest of the UK). And finally to identify key areas for future research to understand the changing role of the SN-OD a central figure in improving donation rates.

Background

Globally, there is a movement to encourage all countries towards self-efficacy, with emphasis on both reducing renal disease and increasing donation and transplantation rates. With the global backdrop of a universal shortage of deceased donors, many countries have employed strategies to increase live donor rates. In the UK, strategies employed to increase donation rates have been established, with emphasis on learning from other countries (Murphy & Smith 2012). Currently there are Parliamentary Bills being debated in both England and Scotland to adopt opt out systems for organ donation.

An audit undertaken by NHS Wales (2015) identified that there were approximately 220 people on the transplant list and of these 12 had died whilst on the list in 2014, with a further 21 dying the year previously in 2013/14. In response to this, the Welsh Government made a commitment to ensure that organ donation became a component part of end of life care and legislated to ensure that everyone in Wales had the opportunity to make their personal will known in relation to organ donation. The subsequent action plan developed to achieve these objectives aimed to ensure that individuals who wish to consent to organ donation and transplantation were able to do so, and that their family were supported during this process by identifying strategic developments in organ donation awareness including:

- Undertaking Public education campaigns aimed at improving the number of people registering on the Organ Donor Register
- Improving referral rates to the Organ Donation Team by staff within Emergency Departments and Critical Care areas of the hospital where patients are most likely to die as a result of Brain Stem Death (DBD) or as a result of a cardiac death (DCD)
- Improving the approach rates to the family by the Senior Nurse for Organ Donation (SN-OD) by adopting an evidenced based approach to the initial request to consider organ donation
- Improving the consent rate obtained from the family when the patient is registered on the Organ Donor Register.

A Welsh Government systematic review of the literature related to opt–out or presumed consent approaches to organ donation between 2008 and 2012 (Palmer 2012), suggested that improvements in the numbers of organs donated could be achieved with the introduction of such legislation. Utilising this data, together with a number of public consultations, the Welsh Government introduced new organ donation legislation, The Human Transplantation (Wales) Act 2015 which establishes a deemed (presumed) consent approach to organ donation. Within this new legislation any individual over the age of 18 years, who has lived in Wales for more than 12 months, can do one of the following:

- Register their decision: On the ODR to become a donor (opt-in to organ donation)
- Do nothing: Indicating that they have no objection to organ donation and will be considered as an organ donor in the event of their death
- Register their decision: Not to become an organ donor

A person dying in Wales, who is not on the objection to organ donation list or who falls into one of the exemptions to this legislation such as those who: lack the capacity to decide, are a child or young people under 18 years, are visitors to Wales or military personally who are serving in Wales, will have been considered to have:

"Deemed Consent" to organ donation and can be identified as a possible organ donor"

The Human Tissue Authority (HTA) (2014) Code of Practice on the Human Transplantation (Wales) Act 2013 requires that the SN-OD undertakes a major role in the implementation of this new legislation. Key to this is the SN-OD's responsibility for the liaison with critical care / emergency care staff to identify the potential donor. Having done so, they are also responsible for the support of the bereaved family and initial review of the Organ Donation Register (ODR), to establish if the potential donor has recorded any objection to donation. If no objection is found, the SN-OD then notifies the deceased's family and friends that their loved one is a potential organ donor as well as informing the CLOD and organ retrieval teams of the potential donation. Thus the SN-OD is key and deserves more attention and a stringer evidence

base to support their practice in enhancing organ donation rates. The following section highlights some of the existing evidence.

Data Sources

Using Medline CINAH, Google Scholar and Embase 95 publications were found that helped to inform this paper. The main focus was the role and the development of the original Donor Transplant Co-ordinator (DTC) from an international perspective. Specifically, the literature associated with the role and development of the Specialist Nurse for Organ Donation (SN-OD) in the UK from 2009 – 2018 was also examined in combination with discussion with clinical experts (including a transplant surgeon and experienced CL-OD and SN-OD).

Discussion

History and Development of Donor transplant Co-Ordinators (DTC)

Across the globe nurses have played an important role in successful organ transplantation practice with the initial approach to potential donor families being a key focus of activity. The complexity of the therapeutic treatment of patients awaiting organ transplantation requires specialist nurse intervention and decisions about when to instigate donor discussions need to be considered carefully and compassionately (Winsett et al 2008). The role of the transplant coordinator (TC) first originated in the United States in the early 1970's, with the US-based International Transplant Nurses Society (ITNS) providing the world's largest global organisation to offer international access to educational programmes and resources for nurses undertaking this role. According to McNatt (2008) one of the challenges in defining the role of transplant co-ordinators is the array of roles and responsibilities that they have to undertake; all of which may vary slightly depending on the local context, country-specific laws, and local health care systems. The precise definition of the role of the transplant co-ordinator within a transplant team has varied depending on the geographical location. Transplant co-ordination refers to the functions and responsibilities involved to support the process of acquiring succesful donations and organising the timely receipt of organs or tissues. Zavala and Crandall (2007) found that transplant teams, usually naming themselves as co-ordination teams, consisted of physicians, nurses, pharmacists, social workers as well as other support staff. Matesanz (2008) however claimed that a co-ordination team requires, at minimum, a specialist physician, surgeon and a number of nurses in order to achieve successful transplantation practice.

The majority of these specialist nurses originated from an adult nursing background and initially undertook a combined role as donor (DTC) and recipient (RTC) transplant co-ordinators. However, Matesanz (2008) suggested that this was perceived to

present difficulties, not least a possible conflict of interest when caring for potential donors whilst also attempting to achieve the best interests of future organ donation recipients. Subsequently the combined roles for the transplant co-ordinators were separated, in the late 1980′s, into the more distinctive DTC and RTC posts. The literature suggests that the main responsibility of the DTC is the identification of a potential donor, management of the organ donation process and the provision of support for the bereaved relatives. In addition to these functions, the DTCs also provide education and support for the staff within critical care areas in relation to the donation and transplant process (Zalewska and Ploeg, 2015).

The role of RTCs includes liaison with national transplant organisations, such as UK Transplant which became National Health Service Blood and Transplant (NHSBT) in 2005, to co-ordinate all retrieval teams and facilitate the acquisition of an organ for potential recipients on a local or wider transplant waiting list. The RTC usually liaises with the rest of the transplant team assessing potential recipient for their transplant suitability. Saviozzi (2010) describes how these RTCs also prepare the patient and their family for life after organ donation and support them during this time. This includes supporting the recipient post transplantation physically, psychologically and socially. They may also be directly involved in managing the recipient's care, for example, autonomously managing the medication of an organ recipient, including altering the dose of immunosuppressant drugs, without the need for authorization from a medical practitioner. However, these extended roles of nurse co-ordinators have been seen mostly in western countries and are dependent on the appropriate educational background of the co-ordinator. This standard of education, to first degree level or above, often influences the scope of their role in the transplantation process (International Transplant Nurses Society 2011). Zalewska and Ploeg (2015) usefully describe how the RTC co-ordinates the transplantation process for the living donor, providing life-long follow up and support for.

Hoy et al. (2011) utilised a questionnaire in the United States containing 21 multiple choice questions and one open-ended questions to explore the roles of the Advanced Practitioner Nurses (APN's) in the organ transplantation process. This survey was sent to 21 medical centres and yielded 53 respondents. The findings suggested that APNs do play a crucial role in caring for transplant patients, however, this role is enacted in different ways and has a varying scope of practice across different transplant centres. Additionally, respondents, in the Hoy et al. (2011), study also suggested a shortage of specialist nurses in the transplant field but put forward that this could be addressed with an increase in physicians, social workers, and local religious leaders rather than an increased number of specialist nursing staff. However, McNatt (2008) argued for a different approach and claimed that as a result of the complexity in organ transplantation, more APNs are required to respond to patient care and management needs. The complex nature of these specialist nursing roles lie at the root of calls for possible replacement by other professionals who are also thought to be able to address social, spiritual and emotional needs. Regardless of the exact configuration of the transplant team, it is now a widely held view that the role of nurses in transplantation practice is an essential requirement throughout the

organ donation process (Arie 2008; McNatt 2008; Moreno and Masllorens 2009; Jawoniyi and Gormley 2015; Roje et al. 2015).

Availability of DTC related to the Donation: International insights

European Donation Rates

In Eire, which has a national management structure utilising DTC's, their introduction was directed at enhancing organ donation (Houston 2011). In Scandinavia several countries have co-operated to provide a shared infrastructure to identify, donate and transplant available organs ensuring their optimum placement. This organisation, Scandia Transplant, which utilizes a system of dedicated medical leads for donation within acute hospitals and DTCs in key regional centres throughout the individual 5 countries in the group, provides high levels of donation rates with Norway achieving the highest of this group at 22.2 donors per million population (PMP). (European Commission 2014).

The most effective organ donation and transplant co-operation system in European countries is found within the South Alliance For Transplant Co-operative where 6 counties, and one observer country (Czech Republic), work together to identify and transplant organs across this group. One member of this group, Spain, achieves the highest donation rate in the world reporting 39.7 donors PMP (European Commission 2014). In the UK the NHS Blood and Transplant (NHSBT) provides the organisational infrastructure that underpins donation and transplant and employs approximately 2020 DTC's who collaborate across the four countries to provide the current donation rate of 20.4 donations PMP.

A review of the donation rates across Europe however reflects a marked difference in the numbers of organs obtained from countries in Northern Europe in comparison with those in Southern Europe. Problems in organ donation have been reported across several Southern Eastern European countries. For example, Turkey reports one of the lowest numbers of deceased organ donors, at 3.6 PMP. Of note, many potential donor centres in Turkey have no transplantation co-ordinators (Harmanci et al 2011). The direct link between Greece, a country with current economic challenges, and which forms part of the South Alliance for transplant co-operative, organ donation would currently appear to be at risk with very low numbers of transplantation and low donation rates of just 4.0 DMP. Moris et al (2016) suggest that the underlying financial crisis in this country may reflect the inadequate healthcare system in and may influence people's attitudes to organ donation there.

One of the key roles of the DTC is to educate and promote organ donation amongst healthcare professionals and the public. These authors also suggested that when there are severe financial constraints with a healthcare system, with limited numbers of DTCs, this key aspect of the role i.e. public promotion of organ donation is more difficult to achieve with an associated negative impact on the organ donation rates of that country.

A great success story in this history is Spain. The Spanish transplantation programme has maintained its position as the clear leader for organ transplantation for over two decades, creating the 'gold standard' organ donation model (Willis & Quigley 2014) When attempting to explain the Spanish success, the 'opt-out' approach for deceased organ donation or 'presumed consent' is most commonly cited. Opt-out means that a patient is presumed to consent to organ donation even if they have never registered as a donor. This has prompted recent moves from other countries, including Wales, to replicate the 'opt-out' system in order to increase levels of organ donation. One country following the Spanish lead in Europe is Croatia, with the second- highest level of donation rates. To achieve these rates Croatia appointed transplant coordinators, introduced a donor hospital reimbursement scheme, conducted a large Croatian public awareness campaign and implemented a donor quality assurance initiative, all of which have contributed positively to their success (Živčić-Ćosić et al 2013).

Asian Donation Rates

The Asian perspective on organ donation would appear to differ from the West. In India, the Transplantation of Human Organs Act in 2011, made the appointment of an appropriately trained transplant co-ordinator an essential prerequisite for hospitals to be registered as transplant centres. In South East Asia, the International Registry on Organ Donation and Transplantation (IRODaT) (2016) reported that there were only 39 from Hong Kong in 2015 from an overall 5.4 DMP. This rate is around one seventh of that in Western countries. However, reluctance to donate organs after death is not uncommon in this region of the world (IRODaT 2016). Japan appears to fare worst with rate as low as 0.66 DMP with figures for mainland China difficult to establish. It has been reported however that following changes to their organ donation approach in 2015, where they stopped the controversial practice of harvesting organ from executed prisoners, this has led to a potential organ donation crisis with an estimated 95% of all donated organs previously being obtained from convicts (IRODaT 2016).

From an international perspective organ transplant coordinators started to emerge in the late 1980s across South East Asia. For example in Hong Kong organ transplant coordinators first established in 1988 are now present in all large regional hospitals. Despite cultural differences, the role of the transplant coordinator does not differ significantly from their Western counterparts, encouraging organ donation and facilitating the matching have donated organs with potential recipients and working closely members of the multidisciplinary health care team. Although public awareness of organ donation has greatly increased in recent years in Hong Kong, the number of people who need a transplant continues to rise faster than the number of donors, prompting examination of the current system (Cheng et al 2005). As with Europe, across Asia transplant activities are limited by the lack of cadaveric donors, attention is being given to ways to increase organ donation.

A review of the donation rates in Asia demonstrate considerably lower levels of organ donation rates from those in Europe which may be the result of a number of factors. For example, less defined organ donation infrastructures which tend to be co-

ordinated by transplant surgeons within a given region. These highly skilled professionals may not have the capacity or appropriate preparation to undertake the complex role of identifying the potential donors and gaining agreement from the bereaved relatives to proceed to donation. Additionally, in these countries there is limited availability and poor definition of the DTC role. These limitations, combined with poor public education in relation to organ donation, as well as social and cultural challenges towards organ donation may be implicated in the low levels of organs obatained.

Insight into and awareness of issues of organ donation in other regions of the world provide valuable understanding of global variations in organ donation practices. These also have relevance due to the multicultural natures of countries such as the UK. Such understanding is essential to augmenting the role of the SNOD and their approach to families for authorisation for donation. Without such global perspectives on attitudes to organ donation, as well as successful and unsuccessful practices and policies, the opportunity for shared learning and how to maximise the potential of DTC input will be reduced.

Educational Preparation for DTC Role

Education for the role of the DTC also varies internationally, for example in the US a Master's educational level is required before the co-ordinator can adopt an autonomous role in the management of the organ recipient patient. Across Europe a range of short specialist education programmes, usually provided by local health providers, are also available to develop the DTC role, however these often vary in level, structure and level of outcome. Successful structured training programmes for DTCs and RTCs do exist in a few countries across Europe.

In Spain, for instance, Transplant Procurement Management (TPM) is a programme endorsed by the European Society for Organ Transplantation (ESOT) and the European Donor and Transplant Co-ordinators Organisation (EDTCO) and has been established as the primary educational programme in transplantation and organ donation co-ordination. The TPM has academic accreditation from the University of Barcelona and promotes knowledge transfer and professional competency development to maximise potential donor and conversion rates (DTI 2017). The International Registry in Organ Donation and Transplantation (2016) suggests that providing appropriate educational for transplant coordinators, such as that available in Spain, can assist with problems of organ scarcity. This is evidenced by Spain's highest organ donation rate in the world with 39.7 DPM.

Development of The Specialist Nurse for Organ Donation in the U.K.

The presence of the specialist nurse within this specialty is significant and is an example of nurse specialisation more generally. The role of the transplant co-ordinator is relatively new in the history of organ donation and transplantation in the United Kingdom (U.K). The role developed from within the nursing profession with the first

transplant co-ordinators being appointed in the UK in 1979. Subsequently, a professional association of co-ordinators was established, the UK Transplant Coordinators Association (UKTCA), that developed standards of clinical practice. Whilst the bulk of individuals holding transplant co-ordinator roles have been nurses, the role has not been developed solely within the sphere of nursing and has also included other professional groups (Peters et al. 2002). This has led to the recent development of the Transplant Co-ordinator, known in the UK as Specialist Nurses for Organ Donation (SN-ODs) following the recommendations within the Department of Health Task Force Report (2008)

These SN-ODS work in close collaboration with medical colleagues and the other members of the multidisciplinary transplant team to implement the UK organ donation strategy and are usually separated into donor and recipient roles. The SN-OD′s functions include ensuring the confirmation of brain-stem death diagnosis and circulatory death in patients and recording this following the performance of the appropriate investigations including virology, blood grouping, tissue typing and ECG. The SN-OD also approaches the family to gain consent for organ retrieval and supports the family up to and beyond the donation process, liaising with UK Transplant to offer the organs for donation. (Zalewska and Ploeg 2015).

As highlighted earlier the SN -OD′s also have responsibility for the care of the donor and the organ placement together with surveillance, procurement and transplantation of the organs obtained. In some situations, the SN-OD performs last offices on the patient once donation is complete and liaises with the family, supporting them in the immediate bereavement phase and informing them of the donated organ's use (Arie 2008). They also are responsible for educating other patients and families and raising the awareness of organ donation (Roje et al 2015). The role is highly specialised and complex and involves practical, emotional and organisational expertise. Given the growth in scope of this role we now move on to look at the practical and theoretical understanding of the SN-OD in organ donation.

Towards a Practical and Theoretical Understanding of the SN-OD's Role

When considering the role of the SNO-OD in the context of organ transplantation it can be seen to reflect many of the features of what Allen (2014) termed a re-conceptualised version of holism within the nursing mandate that is centred on organisational or societal function (in this case promotion of organ donation) as well as individual patient care (donor and family support). Whilst Allen (2014) focuses on contemporary nursing in relation to the world of care provision and organisational function more generally (including bed management, organising the transfer of patients and nurses as sources of patient-related knowledge that ensures the system can function) its relevance goes beyond this sphere. Indeed, the organisational version of holism can be seen to be allied with the multiple practical roles undertaken by SNO-ODs and DTCs whose role and responsibility are comprised of multiple interlinking dimensions. These span the full trajectory of organ donation events and include co-ordinating donor identification, family support, permission seeking and the

close following of legal and ethical requirements and ensuring that bereavement support is available. Furthermore, they also liaise with other, sometimes distant, transplant centres and co-ordinate communication with all members of the transplant team.

This is a role in contemporary nursing that may be considered unique to organ transplantation which suggests the need for ongoing exploration in the light of policy development aimed at improving rates of human organ donation. Whilst previous research has explored some issues related to this role, including descriptions of live donation and associated family support issues (Crombie & Franklyn 2006), as well as the nature of altruism in the donation act itself (Fortin et al 2010), there is now a need to understand how these nursing roles are evolving, and how best to develop them in the future. Included in these new understandings will be the way that expectations to extend the nursing role impacts on its core function of supporting families, and, in turn, how employing advanced clinical and emotional expertise to assist both donors and recipients in this most unique situation, impact on the individual nurse.

The uniqueness of this role must also acknowledge how it balances the support of people caught between often sudden loss and those living with the intense hope for a successful donation before time runs out. It is a unique constellation of circumstances and the nurse occupies a central role within a multi-disciplinary context. The nature of effective praxis in donor and transplant co-ordination is an area that we argue should be subject to further exploration. In particular there is a need to understand the ongoing demands placed on those specialist nurses involved, how multidisciplinarity is played out at the time of donation negotiations (and whether such systems can be improved) and the ongoing professional development and support needs of those nurses involved. As the role varies within and across health systems there is also a need to understand this variation and whether there would be benefit in conducting research comparing different models of the DTCs role and organ donation rates at an international level.

To assist in this process of revealing the changing nature of the role it is also important to consider this unique sphere of nursing practice at a theoretical level. This many help to further contextualise the essence of the SNOD/ DTC role and to describe its changing remit in response to changing donation policy (such as recent deemed consent system introduced in Wales in December 2015).

There are classic theories that might be pertinent to understanding the DTC/ SNOD role including the classic gift theory in relation to blood donation (Titmuss1971) and the normative pressures of donation that may influence the decision; including the pressure and dynamics that exist between giving, receiving and reciprocating as proposed by Fox & Swazey forty years ago (1978). These theoretical insights can help provide understanding of the complex demands and rewards facing all professionals in the transplant arena, but especially nurses who are playing such a key role. Combining theoretical constructions with empirical data from new research may help to promote an increased understanding of these roles, celebrate their success and provide a more evidence-based approach to transplant practice as a result.

In the UK a clearer understanding of the role of SN-OD and their role in the multidisciplinary organ transplant team is needed to demonstrates the many different facets of this specialism, including its responsibilities and skills base. The role of the SN-ODs in the UK is under-researched and, we suggest, poorly understood. Although the literature does provide some evidence of the role of these specialist nurses, limited data exist in relation to their practice and its impact on achieving the goals of the Organ Donation Strategy (DOH 2008). The involvement of the SN-OD appears to be key to the success or failure of a family agreeing to donation and the way that they approach the family may indeed be pivotal in their decision making. Given this it is surprising that the role of the SN-OD has had such limited investigation since its introduction and it is now crucial to develop an understanding of its scope and further potential to enhance organ donation.

There is a need to clarify the complexities faced by these nurses when approaching and supporting bereaved families at such a harrowing time. There is a need for exploration of their nuanced elements of their practice and the clinical decision making processes that these nurses support. This may include, for example, revealing how they respond to the cues being given out by distressed families, as well as the circumstances that are more (or least) conducive to a successful donation from those who are facing the loss of their loved one. The complexities of this role and the balancing of differing priorities and demands within such a delicate situation, clearly merit empirical exploration.

Additionally,despite the existence of an NHSBT development programme for SN-ODs, unlike with other specialist nurses within the UK, there is no formally recognized or nationally accredited academic preparation available. The feasibility of establishing a recognised professional development and education programme for these specialist nurses is timely.

Conclusion

As international policy has developed to encourage higher organ donation rates, so the role of nursing in the transplant process has remained central and needs to be recognised and developed further. The delicate process of caring for relatives at a time of bereavement, and supporting them through the donation process requires to be explored in depth. Given the opportunity to combine the practicalities of this role with the relevant theoretical explanations that already exist, it may be possible to better appreciate the role of the SN-OD (or its equivalent in other countries) in promoting the act of organ donation,. This paper has proposed a number of suggestion and aims to stimulate debate to better understand the changing nature of the nursing role in organ donation strategy.

Ultimately, and despite the valuable roles played by DTC’s and SN-OD’s, there is still effort needed to respond to organ donor shortage and to ensure an ethical, safe and efficient service to offer the chance of donation to as many people as possible who are awaiting an organ transplant. Specialist nursing expertise nursing needs to be recognised as the fulcrum for future developments in this area. As the Governments of England and Scotland currently debate and consult on the future of organ

donor policy, including donor registration, and the approach to families for authorisation, it is important to look to countries with greater success rates and to enhance the full potential of the SN-OD role using an evidence-informed approach.

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